



“Everything Happened So Quickly” Living Through Events Immediately Before and After Initial Breast Cancer Diagnosis: An Exploratory Study of the Experiences of a Group of Women in Cape Town, South Africa

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Abstract

This article provides information on an aspect of the author's research on colored women's experiences of breast cancer and deals specifically with events immediately before and after the initial diagnosis. The experiences of this group of South African women have remained largely undocumented. Individual in-depth interviews were conducted with 30 colored women. Qualitative data were collected and analyzed using thematic content analysis. The main themes that emerged relate to the discovery of the lump, reaction time, response to diagnosis, the question of whether a lumpectomy or a mastectomy should be conducted, counseling and family reactions. The findings show, inter alia, that these women are not accorded sufficient time to deal with the magnitude of the diagnosis and that access to appropriate counseling is insufficient. This study has implications for health professionals and for women in general and suggests further areas of investigation within the field of breast cancer research.

Keywords: Breast cancer; Colored women; Health; Mastectomy

Introduction

The World Health Organization [1] reported that breast cancer continues to remain a common and fatal disease affecting more than 1.2 million women each year around the world. Furthermore, 58% of deaths caused by breast cancer occur in the developing countries [1].

The Cancer Association of South Africa [2] notes that breast cancer is the most prevalent type of cancer among South African women and the lifetime risk of developing breast cancer is 1:33 and this figure is increasing steadily each year. The seriousness of this disease is clearly evident when compared to the prevalence of other types of cancer found among women. In the case of cervical cancer, the lifetime risk for South African women is one in 42 and for uterine cancer it is one in 160 [2]. The prevalence of colorectal cancer is one in 182 South African women and for esophageal cancer it is one in 239 [2].

According to CANSA [2], 6224 cases of breast cancer were diagnosed nationally in South Africa in 2009 with colored women having a one in 22 lifetime risk of developing this disease. It is reported that in the Western Cape alone, 1500 cases of breast cancer are diagnosed annually but, because the cancer registry is voluntary, the cases are underreported and the actual figures are not known [3].

The majority of South Africans are black/African (80.2%) while the colored community is a minority group nationally (8.8%); however, the colored community dominates in the Western Cape (54%), with women making up more than half of this population group [4].

This group is largely working class but is affected by high levels of unemployment. The areas in which these women reside are predominantly mono-racial and are also plagued by high levels of community violence, gang activity [5], drug and alcohol abuse and economic marginalization [6].

Relatively little is known about the experiences of colored women with breast cancer in the Western Cape and it appears that their specific experiences have not been directly documented before. The research presented here is part of a larger exploratory study which examines colored women's experiences of breast cancer. The intention of the study was to gather preliminary data in order to supplement gaps in the literature on the experiences of this particular group of breast cancer survivors.

A review of the literature reveals that there has been a proliferation of studies on breast cancer in recent years and most have been done from either a psychosocial or clinical perspective or in terms of body image, identity and sexuality [7-12]. There has also been an increase in studies on survivorship, coping strategies and partner relationships [13-17].

It appears that these studies were conducted after the women underwent surgery and very little has been written about women's lived experiences before and after the initial diagnosis.

Where studies have included some of these experiences, they were peripheral to the main research question. The intention of this article is therefore to document colored women's concerns and reactions just before and after the initial diagnosis. These existential events, according to Landmark and Wahl [18], are also fundamental in recuperation and survival.

Methods

A snowball sampling method was utilized to recruit women for this study [19]. The initial participant, who is from the designated population group, was recruited during a breast awareness campaign in Cape Town, South Africa. Using the snowball method, 29 women who are survivors of breast cancer were subsequently contacted and interviewed. The inclusion criteria for the present study were that the

woman be diagnosed with breast cancer within the previous five years and that she is from the designated population group.

The timeline for diagnosis of five years ensures a more vivid recollection of the individual's experiences. Informed consent was obtained from all the participants. The University's Ethics Committee approved the consent forms. Participation was voluntary and no monetary compensation was exchanged for participation. Twenty five of the 30 interviews took place in the homes of the participants while the others were conducted at a place convenient to the respondent.

The grounded theory method, which uses observation and data, guided this study. Besides race, other demographic information was obtained from the participants and a 60-minute face-to-face interview was conducted with each woman. The interview schedule consisted of open-ended questions relating to the participants' initial fears, concerns and reactions. The interviews were audio-recorded and transcribed verbatim. Fictitious names were used to guarantee confidentiality and anonymity. The transcripts were analyzed using the inductive approach [20] and themes that emerged during the interviews were identified. An open coding process was utilized to identify varying and recurring sections in the transcripts [21].

The codes were then grouped into six themes and thematic content analysis was applied to the data [20]. The themes that emerged are: the discovery of the lump, the response to diagnosis, the reaction time, the decision between a lumpectomy and a mastectomy, counseling, and informing the family and the family's reaction. Each theme is discussed later in this article under the section on the research findings.

The qualitative nature of this study allowed the participants' own experiences to be prioritized and for their voices to be heard and included in the findings and discussion [22]. The value of this methodology is also noted by the breast cancer researcher, [23] who states that few studies directly quote or include women's perspectives and experiences in relation to their illness.

In addition, Kasper [24] emphasized the imperative to understand breast cancer from the standpoint of women themselves. For Landmark and Wahl [18], it is important to capture the wholeness of women's experiences while Frank's [25] view is that health narratives provide a voice for people living with ill health and allows meaningful insight into their existential experiences with their illness. The current study therefore uses the participant's voices extensively in an attempt to capture and communicate their experiences.

Characteristics of the Participants

Thirty (30) colored women participated in this study and they ranged in age from 17 to 81 years old. The mean age (M) is 49 years and the standard deviation (SD) is 13.1 years. Table 1 below provides selected demographic and medical information of the participants. The women are from varying socioeconomic backgrounds with 21% having had tertiary training, 66% having completed high school and 13% have a primary school level of education. Less than half of the respondents (40%) are in full-time employment.

The majority (54%) of the women are married, 13% are divorced, 13% are single and 20% are widowed. While 57% of the respondents reported a family history of breast cancer, only 21% reported undergoing regular mammograms. Prior to diagnosis, the majority (63%) of the women had not been for a mammogram while 16% were considered too young to go through the procedure.

Participants (N=30)	
Age range	17-81 years of age (Mean: 49; SD: 13.1)
Marital status	
Married	54%
Divorced	13%
Widowed	20%
Single	13%
Education	
Primary school	13%
High school	66%
Tertiary	21%
Employment status	
Full-time	40%
Self-employed	14%
Unemployed	30%
Pensioners	16%
Family history of breast cancer	57%
Mammogram prior to diagnosis	
Regular	21%
Never underwent	63%
Too young	16%
Surgery and treatment received	
Lumpectomy	26%
Mastectomy	74%
Chemotherapy/radiation	100%

Table 1: Demographics and medical history of participants.

Findings

The six themes which relate to the lived experiences of these women are discussed in the sections to follow:

Discovery of the lump

The women spoke at length about the detection of the lump and the action they took thereafter. More than half of the participants (63%) had not had regular mammograms before the appearance of the lump. Therefore, it is not surprising that the majority of the women discovered or felt the lump themselves, that is, by means of self - detection. Most commonly, the women felt the lump while they were in the shower or dressing or while lying in bed. Some individuals noticed a lump as small as a "frozen pea" which they were not concerned about initially, however, they now feel that this was a big mistake. One participant stated that she had had a lump for about a year. Initially it

was small and gave no problems but later it increased in size to that of an egg and it was only at that point that she decided to consult a doctor. In order to make sure that there is in fact a lump in the breast, women often asked their family members or friends to feel the breast and confirm its presence.

One participant, who went for regular mammogram screening, thought she would not develop breast cancer because the mammogram would detect any abnormality before it could become a problem. However, she noticed a lump and, after the diagnosis, it was found that the lump was malignant. This person stated "I followed the rules and yet it still happened".

The younger women who had pain in their breasts told their mothers. The mothers initially thought that the pain was part of a young woman's normal development. Only when the pain became unbearable and, as one individual explained, the lump was "as hard as a rock and stretching my skin, that I was taken to the doctor" (Shireen 17). Laura (27) stated that she had had the lump for ten years before her breast began to swell and her "nipples were oozing". She thought she was pregnant and went to the local clinic.

The women who do regular self-examinations were surprised that the lumps appeared so suddenly. For example, Mary (60) stated that she had always had lumpy breasts and was advised by the doctor not to be concerned. But, one lump she detected was "different, harder" although there was "no pain." Mary stated that this was "a wake-up call" for her.

Janice (46) mentioned that she felt the lump while she was showering. "It was a strange lump, it was never there before and suddenly I spot something unusual. There was no pain, no infection, no oozing, just a big round lump". Kathy (47) stated "One day you feel nothing and the next day there is this lump in your breast. It appears like a thief in the night".

Two of the participants initially felt that they could have hurt themselves in physical activity. Judy (48) stated that the lump felt like a ball and she thought she had strained herself with her housekeeping chores. Maxie (37) thought she had "pulled a muscle" and she said "there was no pain just a bit of discomfort". Both of these women felt there was no need to go to the doctor immediately.

For some of the participants the lumps were discovered by accident. Sue (50) stated that she had unintentionally placed her hand over her breast while lying in bed. She felt an unusual small lump and she had that diagnosed by a doctor. Pat (81) said that her diagnosis was "an act of God as I did not feel a lump, I did not have a lump. I went to the hospital for a bone scan but the machines were faulty. I went for a mammogram instead and a small lump was discovered by the nipple". Joy (68) stated that she did not really know how to examine her breasts and she discovered the lump by accident when she was putting on her bra.

Participants with a family history of breast cancer were more vigilant and regularly examined themselves, but some had doubts about the process. Jane (32), whose mother died of breast cancer, endeavored to be aware of her health in this regard and therefore examined herself after each menses. She mentioned, "After the last cycle the right breast didn't feel normal. There was a bump in the right one and nothing in the left. This made me suspicious. Knowing full well what my mother went through, I consulted the doctor immediately. I thought I was being overcautious".

Another participant, Nancy (48), stated that she discovered a lump in her breast when she was 36 years old. She consulted the doctor who prescribed anti-inflammatory medication and she subsequently did not feel the lump nor was there any pain. A mammogram was never recommended. Nancy was concerned because her grandmother had breast cancer. She was sent for a mammogram when she was 46 and she was diagnosed with breast cancer. Nancy wonders if she could have been spared the experience if the mammogram was done earlier.

One participant was pregnant when she discovered fluid being emitted from the nipple. She stated, "I thought it was part of the pregnancy. The liquid contained traces of blood. I could not go for a mammogram because the appointment coincided with the day I gave birth to my baby. I went a month later and three lumps were discovered at the tip of the nipple" (Sybil 34).

Reaction time

There seems to be no uniformity in the way the participants reacted when they discovered an irregularity in their breast.

According to Evelyn (67), she had the lump for several months but, because it was small and gave no problems at first, she did not react immediately. Mary (54) stated, "When I felt the lump there was no urgency. It was a week after I discovered the lump that I went to the day hospital". For Judy (48) "The lump was not a gradual thing. One day it was there. I carried it for two long weeks before I decided to see the doctor".

Maxi (35) was not concerned at first but, upon examination at the clinic, the nursing sister advised her to consult her doctor immediately. She said:

I had to take my baby for a check-up and casually asked the doctor to examine my breasts. He advised me to go for a mammogram. It was only two weeks later that I actually went for the mammogram. Everything was more important than me going for the x-rays. My needs were secondary.

Laura (27) stated "My breasts were swollen and I thought I was pregnant then. I had oozing nipples. I went to hospital, was given medication but it started again a few weeks later. I knew the lump was in my breast since I was 16. I never took note of it. At the hospital, they said it was not dangerous. I felt sick and was coughing. I thought it was TB. I knew something was wrong but did not know what it was. The swelling continued and I decided that something is definitely wrong. I went to the local clinic and that was when arrangements were made for the mammogram".

Noelle (57) explained that it took her "about two weeks eventually when I finally went to the clinic. I definitely did not think it was too serious and breast cancer did not even cross my mind".

According to Linda (46) "In 2012, I felt the lump and went to a specialist. A biopsy was done and it came out clean. Nevertheless the specialist advised me to have it removed. I did not take notice of his advice. I thought why remove it if there is no cancer or pain. So I just left it because we are women and in many situations we do not consider ourselves as the most important person in our lives, so I just put it aside. Whenever I went to my *General practitioner*, I would tell him to examine my breast. He never advised me to have a mammogram. He said if it is not painful then it's ok. It was only in May 2013 that I was finally diagnosed with breast cancer".

On the other hand, Wendy (48) mentioned that she was actually reprimanded by the radiologist who said, "Why do you women wait so long before coming for a mammogram?"

The researcher noted that those with a family history of breast cancer reacted almost immediately and went for the necessary tests.

Response to diagnosis

There were varied reactions to being diagnosed with breast cancer. Some of the participants thought this was the end for them. Evelyn (67) stated, "Yes, when I was diagnosed I did feel as though this was the end, that I will not live long. I sobbed".

Joy (68) said "I was shocked. It came as a blow to me, like cold water in your face. I did not expect that. The news did not sink in at that time, it is only when I got home did I *realize* that it was cancer. For me, cancer is death. I thought I was going to die. I became emotional. I felt sorry for myself and I did not know what is going to *happen*. I was *living alone*".

Nancy (48) was concerned about how she would handle "the fear ... death... I was probably in denial but more scared. I thought it would have spread to the other organs. I spent four days in my room. I did not want to see or talk to anyone because I felt I had to work through this". Sue (50) associated cancer with death and said, "You always hear about the one that died, not the one that survived."

A few of the participants were in a state of confusion and did not want to believe the diagnosis. Betty (48) explained, "At first I thought this can't be, it is not real. I was in denial" Shireen (17) stated, "At the news I did not really feel anything. No shock or anything. I did not know what cancer was at that time" Janice (46), on the other hand, hoped that the diagnosis was incorrect. She said, "Initially, deep down I expected them to tell me that they are wrong. It is just something that needs to come out or it's just a non-cancerous lump. It happened so fast, you really need to absorb it".

Some of the participants were more pragmatic in their reaction. Mary (54) said, "I was not concerned about myself. I was worried about the children. Each in their own stage in their life and had different concerns about losing a mother. After losing a father, this was like a wake-up call for them".

Sue (50) stated that she was anxious when she heard the news but her concerns were more for her children. She said, "I was scared and worried about my family. Perhaps it is a women's thing. You have your own little fears but you worry about how they feel, how will they cope".

For Sybil (34) the news did not register immediately because she had just given birth. She stated, "I felt very confused but I had to confront and deal with this thing. I felt get it done and over with because my children needed me".

Maxi (35) noted that she was not anxious. For her "something happened, get it over and done and move on... that was always my attitude".

Jane (32) said, "Things go through your mind. If I am sick, who is going to care for my child? I thought, rather leave that, I must think of the positive. I am not going to let him grow up without a mother. He is going to see me. He is going to know me". The views expressed above are similar to the findings of Gonzalez and Davis [26] who noted that the women they interviewed were also fearful and anxious about not being able to care for their children.

A few of the women were not ready for such devastating news. Bernie (60) said, "When I received the results I was not prepared. I felt nothing, I can't explain. I was alone. My family asked if they could go with me. I said no, thinking there is nothing wrong".

Judy (48) explained, "I was with my husband when the cancer was confirmed. I was devastated. I thought, why me? Why did God do this to me?"

Participants with a family history of breast cancer were more accepting of the diagnosis. Laura (27) said, "I was not actually scared because breast cancer is in my family. My aunt has breast cancer and she is still living after being diagnosed five years ago".

Doreen (46) felt positive, as she explained "No, I wasn't really scared because I said I am going to pass through this because if others can then I can. My grandmother had breast cancer and she died of a heart attack at 87. I thought of positive things. I did not think that I am going to die."

Wendy (60) did not associate breast cancer with death even though she had lost a sister through breast cancer. She said, "Reading about breast cancer put my mind at ease because the information stated that breast cancer could be beaten".

Mastectomy or lumpectomy?

The majority of the women were asked to decide whether they wanted a mastectomy or a lumpectomy and 74% of the women had a mastectomy and 26% had a lumpectomy. In three instances the women were told that the cancer was at an advanced stage and the only option was a mastectomy.

Sybil (34) stated, "The doctors said they had to work fast as the cancer was in stage 2 and it was in the milk ducts. If they were to remove half then the cancer may still be behind that. I was fine with their decision".

Janice (46) said, "The doctor mentioned that the cancer was at stage 3 and because the lump inside was so huge, it was the size of a tennis ball, the entire breast had to be removed".

Some of the participants did not have the mastectomy immediately.

Enid (67) stated, "At the hospital I had to undergo several tests to make sure that the cancer had not spread. Thank goodness the cancer was only in the breast. I had to first go on chemotherapy to shrink the lump. I was on chemo for seven months and only after that I had the mastectomy".

In some instances the choice between a mastectomy and a lumpectomy was a difficult one and a few of the women had to consult with significant others before making the final decision. Betty (48) explained that the doctor wanted to operate almost immediately but she wanted to go home and speak to her family before making the final decision. She stated, "They did not really know what to say as this was the first in the family. My sister who works at the hospital advised that it would be better to remove the breast. I had to decide what was best for me. I went back and had the mastectomy". Judy (48) was accompanied by her husband when she consulted with the surgeon. She stated,

"The more I said that I wanted a lumpectomy, the more my husband said cut it off...cut it off! Well I was glad in the end. My husband took the final decision. He told me later that a colleague of his had a lumpectomy and after a while she had to have the breast removed. He

wanted to prevent this from happening to me. I was happy about the decision".

On the other hand, Berny (60) made a personal decision and opted for a mastectomy because the cancer was at stage 2. Her husband questioned her decision and enquired whether that was the only available option. She explained, "I told my husband that it is my body and I do not want the cancer to spread so I am going for the mastectomy. I was happy with my decision".

One participant made her decision based on information she found on the Internet. Through her search Rita (42) came to the decision that, even if the lump was removed, the chance of the cancer recurring is never completely ruled out. Rita stated, "I did not want to go through a second operation, so I decided to remove everything".

Another participant stated that because she had medical insurance she opted for a lumpectomy. With medical insurance she was able to undergo the other treatments, i.e., chemotherapy and radiation, as well as taking expensive medication. It is interesting to note that this participant later mentioned, "If I must have it over again I would rather have a mastectomy because I have lots of swelling due to the radiation and I had another operation to have the nodes removed" (Doreen, 46). Doreen was also fearful of the fact that the cancer may recur.

Shireen (17) described her experience as follows: "The doctors decided that a lumpectomy was best for me. I did not really care. All I wanted at that point was for the lump and the pain to be removed. The pain was so severe the painkillers did not help".

Some of the women faced another dilemma. After receiving chemotherapy they were notified that the lump was completely destroyed but they still had to have a mastectomy. Nancy (48) stated, "The doctor said, based on what was found initially and to make doubly sure that there is no cancer, it has to be a mastectomy. Considering all the facts I wanted the mastectomy".

Two of the participants had a bi-lateral mastectomy. Maxi (35) initially had a lumpectomy but, a few years later, it was discovered that there was "a tumour in the operated breast and fresh one in the other. After having chemo to shrink the tumours both breasts were removed." While Maxi did not have a choice, Sue (50), on the other hand, had a mastectomy and, two years later, wanted to have a reconstruction. She decided to have the remaining breast removed and, according to her, "It was a major decision, I thought I was crazy. I had another mastectomy and the surgeon constructed both. I am happy with my decision *today*" In their study, Grimes and Hou [27] also noted that their participants wanted both breasts removed even though it was not necessary. But, unlike Sue whose decision was based on body image, Grimes and Hou indicate that the participants in their study took the decision because they were afraid of a recurrence of the cancer. Both Maxi and Sue said that they were satisfied with their decision, albeit for different reasons.

Counseling

The participants revealed that they did not receive any professional counselling after being diagnosed. The majority stated that they did not have sufficient knowledge about the cancer and what was going to happen. The women said that some sort of professional counselling would have been preferable after the diagnosis because they were fearful and anxious about the events that were to follow. Shireen (17) stated, "If I had more information it would have been helpful and

would have put me at ease to a certain extent." Two of the women, Judy (48) and Janice (46), saw social workers. However, Judy explained "I thought I am really going to die. The doctor sent me to the social worker to discuss all my problems. I told her I cannot do this on my own. Although my family is there they cannot get into your head. The social worker explained the anxiety attacks that I was experiencing and she put me on some drugs. She advised that I must just talk and the person listening to me must put themselves in my shoes. I did not know what to do and the advice did not help".

For Janice the events around her diagnosis happened very quickly. The day she obtained her results she was also sent to the social worker. She said "The social worker mentioned that they are there for the cancer patients. Anytime if there are questions or if you need to chat, they were there to help. But this did not help me at all".

Informing the family and the family's reaction

After receiving confirmation of the cancer the women had to face the arduous task of informing their families. Hilton, Emslie, Hunt, Chapple and Ziebland [28] note that informing one's family of the cancer appears to be the most difficult part of the process. According to Evelyn (67), "My family was upset but they said it was for my own good. They all accept now, even my husband. He was not with me when I received the news". Betty (48), who is single, stated, "My family encouraged me to be positive". Doreen (46) mentioned, "My husband was more upset he just said he couldn't take it". Because Shireen (17) was still young she felt that it was very traumatic for her parents. They lost a relative through cancer and Shireen said, "They knew what cancer was all about and they were afraid that I was going to go the same way". Mary (54), who is a widow, found it difficult to inform her children. She stated:

Because of my concern for my children, I thought, I must rise above this. They must not really see my fear. My eldest son was in prison. He was the last to know because I had to get permission to visit him. I found it extremely difficult to tell my daughter so I had to ask a friend to come and share this with her. My middle son had a girlfriend who was a nurse so she knew what it entailed and she tried to reassure them. But my children reacted badly, especially my daughter who was very fearful and very concerned. She thought she was going to lose me. Being 14 years old I just reassured her. I had to be strong for her.

Maxi (35) stated: The day I received the news I phoned my husband and told him that it was cancer and that my breasts will have to be removed. I shed a few tears. He did not cry. He said this is going to be a long journey for us. Both of us agreed that our sons needed to know. I wanted to assure them it was not a death sentence because I was positive I was not going to die. When we spoke to them that evening my eldest son wanted to know if I was going to die, that is like a given. I said I believe I am not going to die because I believe in a higher power. They were at peace but I cannot say how they were feeling or if there were unasked questions for them but they were scared.

Sue (50) found a measure of relief because her husband was with her when she received the news but she stated, "Telling the children was not easy. They did not ask anything, they were nervous. The death issue was scary". Pat (81) said that her children were very shocked when they found out that she had to deal with this at this point in her life as she had always been strong and healthy. Laura (27) explained her situation at the time of diagnosis as follows:

I was alone when I got the news. My family was not actually with me throughout this whole thing. Just before I went for the operation, I met

this wonderful guy. He is still with me now. He is the one that made everything so much easier and he is still there for me. If you got someone like that in your life then it is important... You must have someone to care so much about you... otherwise you won't be able to do it.

Rita (42) stated that her daughter thought it was a "death sentence. She was very afraid". Janice (46) said, When I came home-I have a disabled daughter, she does not communicate as normal but she understands us - as I walked in, she looked at my face and I broke down. She wanted to know why I was crying. I also did not want to hide it from her. I was very open. When I told her she was just devastated... She understands everything and she felt she was going to lose her mum. I do most of the things for her. She is in a wheelchair. My eldest daughter was not in. My husband is not very emotional and not supportive. That night he went to tell my daughter. They had a few words in the room and he broke down at that point. I think that was the only part of the journey that he cried a bit.

Jane (32), whose mother died of breast cancer, stated, I came home and had to explain to my dad and brother. My dad has been through this with my mother. It is not news that you want to give to your family. My dad did not expect it. I did not tell him why I went to the doctor in the first place... just wanted to do it on my own. I thought it was a precaution. My dad and brother were shocked. He said we will pray that it is a positive outcome and that we must be strong. He assured me. It's not news you want to bring to your father... The thing that happened to his wife is happening to his daughter. I told my fiancé the same night. He was not happy and was very quiet. The reactions are all different. He did not want anything to happen to me... don't want to lose me. He said all those things and that he will stand by me... he did not run away.

Nancy (48) described her experiences when telling her family as follows, I am a divorcee and I depend a lot on my brother and his wife. When I told them they broke-down, they sobbed. I asked them to support me and that they have to be strong for me, especially my brother. My daughter just walked out of the room. She did not want to hear anything. Because I breast fed her for about three years... people say you don't get breast cancer if you have breast fed... that's a lot of crap. She walked out of the room. I was unable to console her.

According to Rene (46), her husband was with her all the time but did not say anything. She said, Men do not show emotions but it was very emotional for me and our children. They knew what was happening. We sat together and explained everything. My daughter was very emotional. I think everyone was emotional but she showed it more being a woman. I feared more for her than for me because she is a woman, she could be the next victim here.

Discussion

During the interviews the participants spoke at length about their experiences. Each part of their journey has its own significance and elicited different emotions and related to different issues.

The majority of the women in this study discovered the lump themselves. This finding correlates with a previous study which reported that "a vast majority of breast cancers are found by women themselves" [29]. Thind, Diamant, Hoq and Maly [30] also note that it is more common for women to detect their breast cancer themselves and this is especially common among women who have no medical insurance or who do not have regular access to health care prior to

diagnosis. Some of the women discovered the lump accidentally while others discovered it through regular self-examination.

Once a lump is detected, most of the women go through a period of denial, anxiety and fear and do not really know what to do or they hope that the lump will disappear. Because no pain was experienced in majority of the cases, the respondents felt that there was no urgency in having the lump tested. It is interesting to note that some of the participants ask family members or close friends to confirm what they had initially felt in the breast. None of the women mentioned the role their husbands played in discovering the lump. It seems that, initially, some of the women avoided involving their husbands and went for the medical examination alone. This is in contrast to a WHO [31] report which describes the experience of a housewife from New Delhi who found a lump in her breast and wanted to see a doctor about it. She told her husband immediately and he accompanied her to the hospital. A possible explanation could be socio-cultural differences but a few of the women in this study also mentioned that their husbands had their own issues like unemployment and alcoholism. Perhaps further research could shed more light on this.

In line with women's gendered nurturing role, some felt that their health was not a priority and that the needs of their families took precedence and they thus delayed a medical examination. While it is undeniable that the needs of the family are important, it nevertheless seems likely that the underlying factor for stalling was fear and anxiety that the lump could be cancerous. These women therefore find themselves in a precarious position in that they are afraid of what a medical examination will reveal and they therefore avoid the examination which exacerbates their anxiety and/or the spread of the cancer. In retrospect, some of the participants stated that once a lump is detected it is better to have it examined as quickly as possible. For example, Shireen (32) stated:

If you are feeling a lump, it is better to go and find out what it is than sitting and taking all the medications that your friends tell you to take. Rather go and find out than walking around worrying about it. The anxiety of worrying about it can bring the cancer on. So it is better to have yourself checked than living with this fear.

Myrick [32] also confirms that many women are reluctant to have a mammogram because they fear the results. In some senses, these women were also afraid of the Foucauldian clinical gaze and initially felt that the body and especially the breasts are "private". The majority of the women therefore did not go for an immediate examination. Those with a family history of breast cancer reacted immediately and had the necessary tests done. The older women waited after the discovery of the lump for a few months, others for a week or two, before seeking medical attention. Some of the participants felt that other things were more important and needed immediate attention. Some of the women felt that, because the lump was relatively small and there was no pain, there was no reason to take immediate action.

A few of the participants also admitted that the possibility that the lump could be cancerous never crossed their minds. The younger women seemed to have experienced the lump or swelling of the breast for much longer periods and they depended on their mothers for guidance but no immediate action was taken. From the narratives of the participants the belief that if there is no pain then there is no cancer is evident. One woman reported that her GP never advised her to have a mammogram and he reiterated that if there was no pain then there was no need to be concerned. A year later she was diagnosed with breast cancer. In one particular instance, the participant was

reprimanded by the radiologist for not being vigilant and for waiting so long before having a mammogram.

In instances where the women had been for a check-up and/or a biopsy and the results were negative for cancer, or when some of the participants were told that a mammogram was not necessary, the women trusted these results and advice. They were of the view that no further steps were necessary or that there was no urgency to have the lump tested again. These participants stressed the need to have a second and even a third opinion, especially in cases where there is a family history of breast cancer. It seems that the advice "no pain no cancer" is iatrogenic and misleading because most of these women reported no pain and yet were diagnosed with breast cancer. According to the biomedical perspective of health, patients put their trust in the doctors and expect the best advice from them and, for some women, when the doctor's advice did not live up to expectations a sense of doubt and anger developed.

Nancy (48) stated, "2012, 27 March was the worst day of my life. I was told I had breast cancer". According to Sue (50), "Waiting for the results was a traumatic experience for me". The initial reactions to the diagnosis are shock, anxiety, disbelief, numbness, denial, confusion and some respondents hoped that the diagnosis was incorrect. Upon hearing the words "breast cancer" some of the respondents immediately thought about death while others thought about their children. Some of the women also expressed relief that the cancer was only in the breast and had not spread to other organs. It is interesting to note that, at this point, none of the women expressed any concern for their spouses. Their immediate thoughts were for themselves and/or their children. Women with a family history of breast cancer were not as devastated as the other women because they were more prepared and aware that one could survive breast cancer. Prior knowledge about breast cancer also had a mediating effect in that some women read that breast cancer could be beaten and it is not necessarily a "death sentence".

The majority of the participants had a mastectomy and most were given a choice between a lumpectomy and a mastectomy. Three of the women had no option because the cancer was at an advanced stage. Some women were unable to make an immediate decision and consulted members of their families. In these instances, the women felt comforted by the fact that, although the decision was entirely theirs, they could consult with their families. In a few instances there were disagreements between the participants and their spouses but the women were satisfied with the final decision. It is interesting to note that the final decision between a lumpectomy and a mastectomy was based on family knowledge, experience of cancer, family history of breast cancer and information found on the Internet. Some of the women felt that because this was happening to their bodies they wanted complete ownership of the final decision and they saw no need for confirmation from their spouses. While some of the women had the operation almost immediately, others had to undergo chemotherapy in order to shrink the lump. This leads to additional trauma because of the effects of chemotherapy, especially hair loss and the impact of this on a woman's femininity. A few of the respondents also underwent several tests to determine if the cancer had spread to other organs.

The decision between a lumpectomy and mastectomy, in some instances, depended on the financial situation of the individuals. One respondent felt that because she had sufficient funds for continued medical treatment radical surgery could be obviated. It is interesting to

note that only one woman's decision was based on body image and this was a factor which only arose sometime after the initial diagnosis.

At the time of diagnosis, none of the respondents mentioned any concerns about losing a breast and the implication of this for their femininity and sexuality. These issues were insignificant. The need to survive took precedence. Their immediate response was the fear that the cancer might spread to other organs. Nancy (42) stated, "When I received the diagnosis I told myself that I have a diseased organ and it must go. I did not want to live with the fear that the cancer may spread. That was my main concern". This finding is similar to a study by Fallowfield, Hall, Maguire and Baum [33] who found that the fear of losing a breast was not as bad as the fear of knowing that one has cancer. For the majority of the women in this study, it seems that the issues of body image, sexuality, identity or even femininity were stepsisters to survival and were not given any immediate consideration.

Twenty eight (28) of the participants attended a public academic hospital (as a direct consequence of not having any medical insurance) while two individuals were diagnosed at a private medical centre. In both of these instances the women did not have access to professional psychological counselling. At the public hospital some of the women were referred to social workers immediately after the diagnosis. Most of the women stated that they would have preferred more information from the doctors themselves about the procedures that were to follow rather than being sent to the social worker. According to Rottmann, Helmes and Vogel [34], early-stage breast cancer patients need information about the stage of the cancer and treatment options and they prefer verbal information from health care professionals. The results of the current study show that this was seriously lacking.

Janice (46) stated, "Everything happened so quickly, decisions had to be made there and then. One did not have time to let it all sink in and they sent me immediately to the social worker. I had to make a life-changing decision and I was not given time to think about it". The women felt that counselling from a psychologist would have been more helpful rather than from a social worker. Some respondents also felt that they should have been given more time to come to terms with the diagnosis and to inform their families before being sent to the social worker. At that point they were overwhelmed by the diagnosis and still in a state of shock and as Janice (46) mentioned "I am thinking I haven't even told my family yet and here I am with the social worker".

Furthermore, some of the women felt that they were being hurried and experienced a doctor-patient relationship which was dismissive and detached. Bitsika, Sharpley and Christie [35] stress that counseling interventions which take into account an individual's specific circumstances are more likely to succeed than a generalized approach. At the public facilities the women felt that because the doctors had many patients to attend to they were unable to reassure them when they needed it the most. The majority of the respondents clearly stressed the need for more information around breast cancer and the procedures and nearly all the women would have preferred professional counseling.

For most of the participants, attending a public facility and coming from impoverished backgrounds also meant that they had to use public transport. After hearing about the life threatening disease most women felt weak and extremely distressed and thoughts about using public transport in the future, especially after chemotherapy, surgery and other forms of treatment made them even more anxious.

Most of the women were concerned about informing their families. Being fearful for themselves, some of the women tried to put on a

brave front and many stated that they had to be strong for their children and their family. Some of the children wanted to know if their mothers were going to die because of the cancer. Generally the women felt that they did not really know what was going through their children's minds but they were more anxious for their daughters, knowing that breast cancer could also affect them someday. In this study it seems that the daughters reacted more openly than the sons.

Without exception, the women did not want to keep the cancer a secret. They wanted their families to know what was happening. Many of the participants were generally reassured by the concern and support they received from their families. According to Rowland and Massie [36], social support is critical for all women at all stages of the process. However, some did not receive this support. Laura (27), for example, mentioned that it was a lonely journey for her as she did not receive the support she expected from her family. She stated, "You must have someone to care so much about you... otherwise you won't be able to do it". Janice (46) also mentioned that her husband was not very supportive and did not try to reassure her when she told him of the results. Some women stated that their husbands found it difficult to show their emotions. Although some women stated that their husbands were supportive at the initial stage, many were concerned about how their husbands would react after they underwent chemotherapy or after surgery. One respondent thought that when she informed her fiancé he would abandon her. Jane (32), being a single woman, had difficulties informing her father of the outcome of the tests. Jane explained that her father had been through the same situation with her mother and she wished that he did not have to be upset in this way again. It seems that, without exception, the women were fearful and concerned about the cancer but they had to put up a facade and appear strong for their families at the same time.

Implications of the Study

Several concerns and needs of the women came to the fore as the study progressed. These are the "no pain no cancer" advice given by medical personnel which left many women confused and angry when they were eventually diagnosed with breast cancer as well as instances where women felt they were misdiagnosed because they initially tested negative for breast cancer but later tested positive. They stressed that one should have a second and even a third opinion if possible but this is generally only possible for women on a medical aid. For the majority of the participants in this study, who are not on a medical aid, they depended on the initial diagnosis with little chance of a second opinion. Furthermore, almost all of the respondents would have preferred professional psychological counselling and more information on the procedures after the initial diagnosis.

They clearly felt that the social worker was not the person to see when confronted with breast cancer. With 63% of the women not having regular mammograms before diagnosis and the one in 22 chance of a woman developing breast cancer, the need for education and regular screening should be a *sine qua non* for women above a certain age. All the women stressed the need for regular self-examination and mammograms. As the majority of the women could not afford medical aid, the accessibility of medical and screening facilities is also a cause for concern.

While the findings from this research may have implications for the manner in which tests are conducted, or the manner in which medical personnel engage with patients, women also have a responsibility to maintain their health as best they can. The lessons derived through this

study are that all lumps must be checked, no matter how small or inconsequential it may seem to be; one should listen instinctively to one's body as the presence of the lump is a sign that a serious problem may exist; women should have regular mammograms and that there should be breast awareness campaigns to educate and encourage women to have regular screening.

Study Limitations and Further Research

This study does have inherent limitations. For instance, the research presented here is based on interviews with individuals from a certain population group in South Africa. Only a group of 30 female coloured women from the Western Cape were interviewed. Being an exploratory study, it did not include the experiences of women who belong to other population groups and who may come from varying socio-economic backgrounds which may impact differently on their experiences of breast cancer. Neither did the research delve into how breast cancer impacted on the coloured women's femininity and the body image. The study was also confined to a particular area and, therefore, the findings cannot be generalised to represent the experiences of all breast cancer survivors in South Africa.

These limitations, however, provide a platform for further research in relation to breast cancer. For example, future researchers may consider how the marginalisation of coloured women impacts on their coping strategies. A cross-sectional study comparing the experiences of women from different cultural, racial and socio-economic backgrounds will also broaden the understanding of the experiences of breast cancer survivors in South Africa. It is necessary to ascertain to what extent South African women generally make use of mammography screening and to gauge the efficacy of the education around breast cancer and early detection.

In addition, a nuanced understanding of the notion of "femininity" in relation to breast cancer could ease the anxiety women experience when they have to have a breast or part of it removed. There is also a need to understand why women diagnosed with breast cancer are sent to social workers and not psychologists. The apparent lack of involvement of spouses and the impact of the wife's illness on the husband are important areas that require urgent attention also.

These studies may have further implications for policies around women's health with specific reference to breast health and breast cancer.

Conclusion

Although the experiences of the group of coloured South African women in the Western Cape who were interviewed may not differ widely from the experiences of other breast cancer survivors, it is nevertheless important to give these women recognition and a voice because of their marginalised status in the South African context. Many women commented on the cathartic nature of the interview and expressed surprise and gratitude that someone wanted to hear exactly what had happened to them during their cancer experience and this gave them a sense of recognition and validation.

The contributions of this study, besides documenting the experiences of a particular group of women in South Africa, are that:

(a) It highlights the importance of acknowledging the initial experiences of breast cancer survivors and the need for more time to process the diagnosis; (b) It emphasises the need for professional psychological counselling; (c) It suggests that access to health facilities,

especially for mammogram screening, is crucial for women who do not have medical insurance and who have to depend on public transport; (d) It brought to the fore lessons that women must take note of in terms of their health; and (e) Being an exploratory study, it raises several pertinent issues which require further interrogation in order to adequately understand women's experiences in relation to breast cancer.

Self-reflection

As a woman listening to these survivors, the researcher became so immersed in the details of their experiences that for days and weeks after the interviews the researcher was acutely aware of subtle reactions and slight changes around her breast area and was constantly dogged by the question "Do I have breast cancer"? This feeling of over-identification is also noted by Johnson and Macleod Clark [37] who found that for some researchers dealing with sensitive topics, e.g. cancer, left them wondering if they too had this disease [38-40].

References

- WHO (2015) Breast Cancer: Prevention and control.
- CANSA (2015) Fact sheet on breast cancer in women.
- Fokazi S (2011) Cancer victim talks of family's battle with illness. Cape Argus.
- Statistics South Africa (2014) Mid-year Population Estimates.
- Shields N, Nadasen K, Pierce L (2013) Community violence and psychological distress in South African and US children. *Int Perspect Psychol: Research, Practice, Consultation* 2: 286-300.
- Daniels D, Quinton A (2010) Breaking with township Gangsterism: The struggle for place and voice. *African Studies Quarterly* 11: 45-57.
- Avis NE, Crawford S, Manuel J (2004) Psychosocial problems among younger women with breast cancer. *Psychooncology* 13: 295-308.
- Schulz U, Mohamed NE (2004) Turning the tide: benefit finding after cancer surgery. *Soc Sci Med* 59: 653-662.
- Fallbjork U, Frejeus E, Rasmussen BH (2012) A preliminary study into women's experiences of undergoing reconstructive surgery after breast cancer. *Eur J Oncology* 16: 220-226.
- Rasmussen DM, Hansen HP, Elverdam B (2010) How cancer survivors experience their changed body encountering others. *Eur J Oncol Nurs* 14: 154-159.
- Manganiello A, Hoga LA, Reberte LM, Miranda CM, Rocha CA (2011) Sexuality and quality of life of breast cancer patients post mastectomy. *Eur J Oncol Nurs* 15: 167-172.
- Kaiser K (2008) The meaning of the survivor identity for women with breast cancer. *Soc Sci Med* 67: 79-87.
- Schetter CD, Feinstein LG, Taylor SE, Falke RL (1992) Patterns of coping with cancer. *Health Psychol* 11: 79-87.
- Stanton AL, Snider PR (1993) Coping with a breast cancer diagnosis: A prospective study. *Health Psychol* 12: 16-23.
- Lethborg CE, Kissane D, Burns WI (2003) "It's Not the Easy Part." The experiences of significant others of women with early stage breast cancer at treatment completion. *Soc Work Health Care* 37: 63-85.
- Coggin C, Shaw-Perry M (2006) Breast cancer survivorship: Expressed needs of black women. *J Psychosoc Oncol* 24: 107-122.
- Manne SL, Norton TR, Ostroff JS, Winkel G, Fox K, et al. (2007) Protective buffering and psychological distress among couples coping with breast cancer: The moderating role of relationship satisfaction. *J Family Psychol* 21: 380-388.
- Landmark BT, Wahl A (2002) Living with newly diagnosed breast cancer: A qualitative study of 10 women with newly diagnosed breast cancer. *J Adv Nurs* 40: 112-121.
- Neuman WL (1994) Social research methods, qualitative and quantitative approaches. Boston: Allyn and Bacon.
- Ezzy D (2002) Qualitative analysis, practice and innovation. Sydney: Allan and Unwin.
- Henning E, Rensburg W, Smit B (2004) Finding your way in qualitative research. Pretoria: Van Schaik.
- Ingrisch D (1995) Conformity and resistance as women age. In: Arber S, Ginn J, Connecting Gender and Ageing: A Sociological Approach. London: Routledge pp: 151-165.
- Bredin M (1999) Mastectomy, body image and therapeutic massage: A qualitative study of women's experience. *J Adv Nurs* 29: 1113-1120.
- Kasper AS (1994) A feminist, qualitative methodology: A study of women with breast cancer. *Qual Sociol* 17: 263-281.
- Frank AW (1998) Just listening: Narratives and deep illness. *Family, Systems and Health* 16: 197-212.
- Gonzalez SJ, Davis C (2012) Understanding the unique experiences of undocumented Hispanic women who are living in poverty and coping with breast cancer. *J Immigrant and Refugee Studies* 10: 116-123.
- Grimes TS, Hou S (2013) "A Breast ain't but a sandwich." Narratives of Ella, an African American social worker breast cancer survivor. *Social Work in Public Health* 28: 44-53.
- Hilton S, Emslie C, Hunt K, Chapple A, Ziebland S (2009) Disclosing a cancer diagnosis to friends and family: A gendered analysis of young men's and women's experiences. *Qual Health Res* 19: 744-754.
- Kearney AJ (2006) Increasing our understanding of breast self-examination: Women talk about cancer, the health care system, and being women. *Qual Health Res* 16: 802-820.
- Thind A, Diamant A, Hoq L, Maly R (2009) Method of detection of breast cancer in low-income women. *J Women's Health* 18: 1807-1811.
- <http://www.searo.who.int/entity/noncommunicabledisease/advocacy/worldcancerday2014/en>
- Myrick S (2002) The patient perspective: Surviving breast cancer. *The Breast Journal* 8: 119-120.
- Fallowfield LJ, Hall A, Maguire GP, Baum M (1990) Psychological outcomes of different treatment policies in women with early breast cancer outside a clinical trial. *BMJ* 301: 575-580.
- Rottmann N, Helmes AW, Vogel BA (2010) Patients' needs and experiences at breast cancer diagnosis: How perceived threat influences the physician-patient interaction. *J Psychosoc Oncol* 28: 157-172.
- Bitsika V, Sharpley CF, Christie DRH (2010) "What made me unhappy." Experiences of, and responses to, lifestyle changes in breast cancer patients. *Br J Guidance Counselling* 38: 179-189.
- Rowland JH, Massie MJ (1998) Breast Cancer. In: Holland JC, Psycho-oncology. Oxford, New York pp: 380-401.
- Johnson B, Clarke JM (2003) Collecting sensitive data: The impact on researchers. *Qual Health Res* 13: 421-434.
- Fransch CJP (2010) "We would have no name": The porosity of locational and racial identities among the 'coloured' communities of Stellenbosch. *African Studies* 69: 403-422.
- Isaacs-Martin W (2014) National and ethnic identities: Dual and extreme identities amongst the coloured population of Port Elizabeth, South Africa. *Studies in ethnicity and nationalism*, 14: 56-73.
- Seekings J (2008) The continuing salience of race: Discrimination and diversity in South Africa. *J Contemporary African Studies* 26: 1-25.